

**A Family Handbook
on Future Planning**

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and

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CHAPTER 6 GOVERNMENT BENEFITS

Supplemental Security Income (SSI)

SSI is a federal income supplement program funded by general tax revenues (not Social Security taxes). It is designed to help people who are aged, blind, and disabled who have little or no income. It provides cash to meet basic needs for food, clothing, and shelter.

SSI benefits are not based on an individual's prior work or a family member's prior work. To get SSI, a person must have limited income and resources. In most states, SSI recipients also can get Medicaid (medical assistance) to pay for hospital stays, doctor bills, prescription drugs, and other health costs. SSI recipients may also be eligible for food stamps in every state except California.

To get SSI, a person must be at least 65 years old, or be blind or disabled. An adult must be unable to work due to a physical or mental impairment which has lasted or is expected to last at least 12 months or result in death. A child under age 18 is eligible if he or she has a physical or mental condition or conditions that can be medically proven and result in marked and severe functional limitations, and the condition(s) must have lasted or be expected to last at least 12 months or end in death. If age 18-22 and a student, the adult disability definition applies.

Because SSI is an income support program, monthly eligibility is based on the financial need of an eligible individual. Congress established a threshold amount that it says is the amount of federal support people need for food, clothing and shelter. Called the federal benefit rate (FBR), this amount is adjusted every year for cost-of-living changes. In 2004, the FBR is \$564. In some states, the federal payment is supplemented to make up for regional living costs.

Income considered in determining SSI eligibility includes earnings from employment, pension, alimony, interest, and food, clothing and shelter given on a regular basis. Any amount of money that is given as a gift or inheritance is counted as income. These are some of the reasons to consider a special needs trust for individuals with mental retardation and related developmental disabilities. Resources are assets that the individual owns such as cash/bank accounts, life insurance, land and personal property. To qualify for SSI, an individual is allowed to have assets of no more than \$2,000. Owning a home is allowed if the person lives in it, as is a car if it is needed for work or medical treatment and for other specified reasons. The face value of a life insurance policy cannot exceed \$1,500. Certain types of resources do not count, such as food stamps, energy assistance and federally subsidized housing.

Social Security Disability Insurance (SSDI)

Social Security Disability Insurance (SSDI or DI) is a federal disability insurance program funded by a portion of the Social Security FICA taxes a worker and employer pay on a worker's earnings. An eligible worker who is disabled can receive monthly cash payments to replace some of his or her lost income and Medicare medical supports. Medicare provides medical coverage beginning two years after the benefits start.

SSDI differs from SSI in that it is not based on financial need. It may be based on your child's own work record or on the parent's work record. For a child with a disability to receive benefits on the parent's work record after age 18, the following rules apply:

- The disabling impairment must have started before age 22, and;
- He or she must meet the definition of disability for adults.
- The parent who paid in to Social Security must become disabled, retire or die in order for the disabled adult child to receive benefits.

NOTE: An individual may become eligible for a disabled child's benefit from Social Security later in life. This is called Disabled Adult Child benefit (DAC). For example, a worker may retire and start collecting Social Security retirement benefits at age 62. He has a 38-year old son who has had cerebral palsy since birth. The son will start collecting a disabled "child's" benefit on his father's Social Security record. To be eligible for DAC benefits, the individual must be an unmarried child of a person already receiving SSDI, Retirement Benefits, or who died while covered by Social Security. The child's benefit is equal to 50% of the parent's Social Security when the parent retires and 75% of the parent's Social Security when s/he dies. A person receiving only DAC benefits can have unlimited assets and so can receive an inheritance without affecting DAC benefits.

Disability under your own Social Security is based on your inability to work. You are considered disabled under Social Security rules if you cannot do work that you did before and you cannot adjust to other work because of your medical condition(s). Your disability must also last or be expected to last for at least one year or to result in death.

To qualify for benefits, you must first have worked in jobs covered by Social Security. Then you must have a medical condition that meets Social Security's definition of disability. In general, Social Security pays monthly cash benefits to people who are unable to work for a year or more because of a disability.

Benefits usually continue until you are able to work again on a regular basis. There are also a number of special rules, called "work incentives," that provide continued benefits and health care coverage to help you make the transition back to work. If you are receiving Social Security disability benefits when you reach age 65, your disability benefits automatically convert to retirement benefits, but the amount remains the same.

In addition to meeting the Social Security Administration's definition of disability, you must have worked long enough--and recently enough--under Social Security to qualify for disability benefits. Social Security work credits are based on your total yearly wages or self-employment income. You can earn up to four credits each year. The amount needed for a credit changes from year to year. The number of work credits you need to qualify for disability benefits depends on your age when you become disabled. Generally, you need 40 credits, 20 of which were earned in the last 10 years ending with the year you become disabled. However, younger workers may qualify with fewer credits.

Children and Disability Benefits

Under the SSI program, a child from birth to age 18 may receive monthly payments based on disability if he or she has an impairment or combination of impairments that meet the definition of disability for children. The family must have limited income and resources to qualify. (See SSA Publication No. 05-10026 in Resource section.)

Children under age 18 may also receive Social Security dependents benefits based on the record of a parent who is collecting retirement or disability benefits from Social Security, or survivors benefits based on the record of a parent who has died. This benefit is not based on the child's disability. However, those benefits can continue to be paid into adulthood if the child is disabled. To qualify for these benefits, an individual must be eligible as the child of someone who is getting Social Security retirement or disability benefits, or of someone who has died, and that child must have a disability that began prior to age 22.

Medicaid

Medicaid is a health insurance program for low-income individuals who meet the other eligibility criteria set by the federal government such as having a disability. It is a federal-state program that varies from state to state. It is run by state and local governments within federal guidelines. All states cover a minimum set of services including hospital, physician and nursing home services. States have the option of covering an additional 31 services including prescription drugs, hospice care and personal care services.

Since it is a "needs-based" program, most individuals who qualify for SSI will qualify for Medicaid. In many states, this is an automatic process. In others, the individual must submit a separate application for Medicaid.

It is important for families to know that Medicaid, in addition to providing health care, is the funding source for the majority of other services offered in the developmental disabilities system. Almost all residential services are funded through Medicaid. The Medicaid Home and Community-Based Services (HCBS) Waiver funds such services as supported living, supported employment and family support.

The Home and Community-Based Services Waiver legislation provided a vehicle for states, for the first time, to offer services previously offered in institutional settings to serve people in their own homes and communities. HCBS waivers afford States the flexibility to develop and implement creative alternatives to placing Medicaid-eligible individuals in hospitals, nursing facilities or intermediate care facilities for persons with mental retardation.

The Act specifically lists seven services that may be provided in HCBS waiver programs: case management, homemaker/home health aide services, personal care services, adult day health, habilitation, and respite care. Other services, requested by the state because they are needed by waiver participants to avoid being placed in a medical facility (such as non-medical transportation, in-home support services, special communication services, minor home modifications, and adult day care) may also be provided, subject to federal Center for Medicare & Medicaid Services (CMS) approval. The law further permits day treatment or other partial

hospitalization services, psychosocial rehabilitation services, and clinic services (whether or not furnished in a facility) for individuals with chronic mental illness.

Medicare

Medicare is a federal health insurance program. Medical bills are paid from trust funds which those covered have paid into. It primarily serves people over age 65, whatever their income, and serves younger disabled people and dialysis patients. Beneficiaries who are disabled are eligible to receive Medicare after a two-year waiting period.

Medicare has two parts – Part A (hospital insurance) and Part B (medical insurance). Part A is paid for by a portion of the Social Security tax of people still working. It helps pay for inpatient hospital care, skilled nursing care, and other services. Part B is paid for by monthly premiums of those who are enrolled. It helps pay for such items as doctor's fees, outpatient hospital visits, and other medical services and supplies.

Dual eligible beneficiaries who are also eligible for Medicaid can receive additional assistance from their State Medicaid program. For example, most Medicaid programs will pay the Part B premiums. Medicaid will also supplement Medicare coverage by providing services and medical supplies that are not covered by Medicare. Services that are covered by both programs will be paid first by Medicare and the difference by Medicaid, up to the State's payment limit. Medicaid also covers additional services (e.g., nursing facility care beyond the 100 day limit covered by Medicare, prescription drugs, eyeglasses, and hearing aids).

Applying for Benefits

An initial application for disability supports under the Social Security program should be made at your local SSA office (call 1-800-772-1213 to find the office nearest you). Applicants for SSDI benefits (but not SSI or children's benefits) can now apply online by going to <http://www.ssa.gov/applyforbenefits/> and following the instructions.

No application for disability benefits is completed until a written and signed application is submitted. Likewise, one cannot be officially denied or awarded benefits until that written application is reviewed by SSA and a formal decision has been made. SSA may get some of the initial application information by phone, but it is best to complete a written application for disability benefits as soon as possible.

You should have a knowledgeable advocate who understands Social Security policies to assist you in completing the complicated application. Submitting a signed, written application provides documentation of the application date. This date is very important should an SSA decision need to be appealed. If the appeal is successful, benefits can start on the documented "protected" date when the application was made.

Resources on Government Benefits

Scarborough, D. (1990-2003). *Accessing Social Security Disability Benefits to Provide Vocational and Educational Opportunities for People with Disabilities*. National training curriculum for disability service organizations on accessing Social Security disability programs. Available from author, d.scarborough@passNetwork.org.

Scarborough, D. (2003). *Appealing a Decision by the Social Security Administration for Disability Benefit Eligibility*. The Arc of the United States. Available on-line: <http://www.thearc.org/afcsp/appeals.htm>

Scarborough, D. (2003). *How the Social Security Administration Defines Disability for Social Security Disability Benefit Eligibility*. The Arc of the United States. Available on-line: <http://www.thearc.org/afcsp/defdisability.htm>

SSA Publication No. 05-10029. *Disability Benefits*. February 2003, ICN 456000. Available on-line: <http://www.ssa.gov/pubs/10029.html>

SSA Publication No. 05-10026. *Benefits for Children With Disabilities*. August 2001. Available on-line: <http://www.ssa.gov/pubs/10026.html>

Social Security Disability Insurance (SSDI) Program: <http://www.ssa.gov/disability/>

Supplemental Security Income (SSI) Program: <http://www.ssa.gov/notices/supplemental-security-income/>

CHAPTER 4 PROTECTING INDIVIDUALS: GUARDIANSHIP AND ALTERNATIVES TO GUARDIANSHIP

The majority of people with mental retardation and related developmental disabilities can manage their own affairs with informal assistance and guidance from others, such as family and friends. If guardianship is necessary, it should be tailored to the person's needs. The appointment of a guardian is a serious matter because it limits a person's independence and rights. (See The Arc's position statement on guardianship at the end of this document, page 41.)

There is no magic formula to determine when or whether guardianship or limited guardianship is appropriate. An individual's abilities and needs must be the paramount consideration in deciding to seek guardianship or to find other less-restrictive approaches for legal assistance, protective service or problem-solving.

You should learn the guardianship and protective services laws in your state and consult with other parents, your chapter of The Arc and professionals in making this determination.

What is Guardianship?

Guardianship is a court-approved legal relationship between a competent adult (known as a guardian, limited guardian, conservator, etc.) and a minor or adult with a disability or other incapacitated person (known as a ward). It gives the guardian a defined degree of authority and duty to act on behalf of the ward in making decisions affecting the ward's life. Each state has its own specific laws on guardianship. There is no uniform national guardianship law. However, the following generally describes the guardianship laws throughout the United States:

Guardianship of a Minor Child

By state law, all parents have guardianship power over their own minor children. The guardianship law for minors does not distinguish between children with mental retardation and those without a disability. All children up to a certain age, usually eighteen years, are under their natural parents' guardianship.

Even in divorce, both parents remain the lawful, natural guardians of the children. However, in determining the child's custody, the court determines which parent has priority in exercising the legal authority of the natural guardian.

If one parent dies, the surviving parent continues as natural guardian. If both parents die before the child reaches legal adulthood, the court appoints a guardian to replace the natural guardian. The court appointed guardian will remain in this role until either a court removes the guardianship or the ward reaches the age of majority, whichever comes first.

In choosing a guardian for a child, most state laws instruct the court to follow a preferred list of people in the parent's will. Some parents do not have a will or did not list in a will the preferred guardians for their children. In these cases, the court will usually consider the state social services department or whomever is available, capable and willing to accept the

responsibility. Appointment also depends on the court finding the preferred person(s) qualified and approving the person(s) as guardian(s).

Guardianship of an Adult

Guardianship is a legal, not medical determination. When people with mental retardation and related developmental disabilities become adults, they have all the legal rights and responsibilities of any adult. A doctor, psychologist, social worker or attorney cannot assign legal guardianship over a person. Only the court can make one person the guardian of another person. The court's decision is usually based on the person's abilities to handle personal decisions, money, property and similar matters. The incapacity (or legal inability) to handle these matters is the grounds for a guardianship, not mental retardation or other disabilities.

The Need for Guardianship

Decision-making about the need for and extent of guardianship for an adult with mental retardation should not be made solely on the basis of psychological testing or the presence of mental retardation. Too often in the past, courts have removed all decision-making rights from an individual with mental retardation based simply on the fact of a diagnosis. Appointment of a guardian should be made only to the extent necessary for the protection and welfare of the individual, and based on the individual's abilities and needs. Guardianship should be established to ensure the person retains as much independence as possible, especially in areas in which he or she possesses capable decision-making skills.

There may be different reasons why an individual with mental retardation and related developmental disabilities may need a guardian. Some common reasons are:

- The person has assets he or she cannot adequately manage. Someone is needed to be sure the assets are secure and used for the intended purpose.
- The person needs medical care or other services that will not be provided unless there is a clear understanding about the person's legal capacity to consent to treatment or services. Health and service providers are becoming more concerned about liabilities when providing services to someone who may not have the capacity to make an informed consent to treatment or services.
- Parents or siblings cannot get access to important records or provide other help without guardianship. As a legal adult, a person with mental retardation must often give consent for the release of health and other records to parents or others. Health and service providers unsure of the person's ability to give consent may require documentation of the person's legal capacity before allowing access to records without the person's consent. (Note: The recent implementation of the federal law, the Health Insurance Portability and Accountability Act, or HIPPA, creates new and significant penalties for health care providers and others who release records without approved consent of the patient or client.)
- An individual with mental retardation may require an advocate's help, someone who has a legal status or relationship to that person.

For many parents, the need to petition the court for guardianship will be quite clear. For other parents, deciding on the need to petition the court for legal guardianship may be difficult.

To help with this decision, you should consider the guardianship laws in your state and the alternatives to guardianship.

Types of Guardianship

Types of guardianship vary depending on state law. State laws may differ in defining incapacity, interpreting the guardian's duties and qualifications, terminology, reporting, documentation, costs and other areas related to guardianship. In general, types of guardianship fall into several categories:

Guardian of the Person or Property

Guardianship is sometimes characterized as “guardian of the person” or “guardian of the estate.” In guardian of the person, the individual needs a guardian to decide personal issues. These decisions may include where to live, consent for medical treatment and signing for services.

The court will usually identify specific decision-making areas under guardianship of the person. Courts frequently require periodic reports from the guardian about the guardian's actions over the course of the year or other period.

A guardian of the estate, called a conservator in most states, usually has power just over the ward's money or property, not the individual's personal matters. Some states also do not require a judgment of the person's incapacity for a guardianship of the estate. The court can base the need for conservatorship just by finding the person unable to manage assets or property.

The court requires this type of guardian to protect the person's property and use it for the person's care, support, education and other areas of general welfare. The guardian of the estate must use the ward's money for the ward's care and account periodically to the court. Guardians who have foolishly invested or embezzled their ward's money may have to pay it back from the guardian's own money or face criminal charges for fraud. They must also keep good records and make them available to the court. Some states require this guardian to put up a bond.

Full Guardianship

A full or plenary guardianship basically includes guardianship over all the person's personal and property decision-making. It is usually a collection of all the powers and responsibilities mentioned above. Full guardianship is quite common, as it is the kind with which courts are most familiar.

Since full guardianship involves controlling every aspect of the person's life, it is the most restrictive. Full guardianship is useful for individuals whose mental retardation is so severe that they are not capable of making proper decisions. Before choosing full guardianship, alternatives, including limited guardianship, should be explored.

Limited Guardianship

Many states have designed laws for “limited guardianship” to encourage a person to keep as much control as possible over his or her own life. Under this legal approach, the guardian has authority over the ward only in specifically defined matters. Every decision outside of those defined areas remains with the individual who has mental retardation. This form of guardianship allows the legal guardian to decide only in areas where the person is not capable.

Limited guardianship does require more attention from the court, attorneys and guardians to ensure it is specific to the individual’s needs. The court, in considering limited guardianship, also must try to foresee all the individual’s future legal needs. For example, an unpredictable legal situation might arise that is not covered under the limited guardianship. The guardian may not have the authority to provide needed protection and may have to return to court to get more decision-making power.

Note: Guardianship does not always fall under just one or the other of the above categories. In many states, the court may authorize a mix of guardianships. For example, a person may need full guardianship of the estate and only limited guardianship over certain personal matters.

Temporary Guardianship

Some states allow guardianship for a limited time. If a legal problem arises from a specific situation, the court can issue a “protective order” or temporary guardianship. Under a protective order, the court can give another person, a public guardian or corporate guardianship program (these last two are discussed later) the legal authority to handle the specific situation. When the problem is resolved, the order ends with no permanent guardianship.

Temporary guardianship usually applies to temporary situations such as those caused by drugs, acute illness or special medical situations. It has limited uses for long-term, reoccurring medical situations or incapacities due to disability. This allows family members or an agency to obtain temporary guardianship if medical or other treatment is necessary, but not given due to the person’s questionable ability to consent. Once the person has treatment provided, the guardianship is removed.

Alternatives to Legal Guardianship

Before pursuing guardianship, parents should first consider using less intrusive, even non-legal, measures. For example, someone who lives alone and has trouble managing money may not need a legal guardian. Rather, the person may only need a restricted bank account and the occasional visit of a case manager, family member or other trusted person for help in budgeting money and paying bills.

Below are some methods or services that may provide the protections or supports a person may need now or in the future. These do not always carry the “legal weight” of guardianship. Instead, they (1) may only legally protect the person or property to a limited degree; or, (2) are non-legal services or options that may meet the individual’s needs instead of

legal guardianship. It is a good idea to consult with a knowledgeable attorney experienced in disability issues to make sure alternate plans do not inadvertently jeopardize government benefits or create other legal problems.

Representative Payee

Some individuals with disabilities receive government, military and other benefits. They usually receive these benefits by check made payable to the recipient. Many individuals with mental retardation can manage this money. However, others may not have good money management skills or are vulnerable to exploitation by others.

The administrator of these benefits, such as the Social Security Administration (SSA), may sometimes assign a representative payee for a recipient of these benefits. This payee receives and distributes the benefits when the individual with mental retardation cannot manage the check. In some cases, family members serve as Representative Payees. However, in many instances non-governmental organizations (i.e., public guardian offices, community mental health centers, clubhouses, or even for-profit companies) serve as Representative Payees. The payee must regularly account to the benefit's administration on the use of the benefit check, and is liable to repay money if it is mismanaged.

The decision to assign a representative payee to someone is usually based on non-legal documents such as a doctor's report. Contact your local SSA office or administration office of other benefits for more information on the representative payee system. You may also find information on SSA's web site: <http://www.ssa.gov/payee/>.

Joint Property Ownership

Families often worry about their son or daughter's skills in managing their own home. They may fear the property would be poorly maintained, lost due to a tax lien or sold against their wishes. These potential problems may be avoided by placing property in joint ownership under the names of the son or daughter with mental retardation and another trusted person. However, property worth more than a certain value, if not connected to the person's home, may jeopardize a person's SSI benefits. Joint ownership may also be subject to other potential problems. For example, if a non-disabled sibling who co-owns the property was to divorce, the spouse of that person could claim a portion of the co-owned property under a community property settlement. The jointly owned property could also be subject to creditors if that non-disabled sibling were to have financial problems.

Joint Bank Account

Most banks can assist with creating a bank account to help manage money. For example, benefit checks can be directly deposited and certain bills automatically paid. It may also be possible for spending money to be sent regularly to the individual from his or her account. A joint bank account can help an individual manage money and prevent excessive expenditures.

Trust Account

Setting up a trust, discussed earlier in this publication, may protect money or other property from being overspent or mismanaged. A carefully written, restricted trust may provide financial protections that relieve the need for other legal protections such as guardianship.

State Programs

Some states have laws that can protect the individual or the individual's property without having to rule the person incapacitated. A state may contract with a nonprofit advocacy and guardianship agency to provide trusteeships and protectorships for certain individuals with disabilities who may need assistance or protection. There are usually certain stipulations to using these types of services and not all states have laws that authorize these programs. Check with your chapter of The Arc or local mental retardation agency to determine if such laws are in effect in your state.

Living Will/Healthcare Directive and Durable Power of Attorney for Health Care

A living will or healthcare directive spells out the sort of medical treatment an individual wishes or does not wish to receive when the person is unable to communicate that information. A doctor who receives a properly signed and witnessed document is supposed to honor the instructions or transfer the patient to a doctor who will. Often used to specify the withholding of life prolonging treatments, a living will could indicate that the individual would like all the medical treatment that is available.

A durable power of attorney for healthcare is a legal document that gives another person (typically parents) authority to make medical decisions for the individual with mental retardation. Since the document does not necessarily state the type of medical treatment the individual prefers, the person with power of attorney has the authority to make medical decisions. However, if the individual also has a living will, the two documents should work together to ensure the person receives the desired type of treatment. Hospitals and senior centers often provide help with healthcare directives free of charge and have standard forms that can be used. You may also have your attorney handle this as part of your plan for your family member. The durable power of attorney for healthcare must be written and notarized. It may be helpful to have supporting documentation that the individual with mental retardation is competent to designate someone as power of attorney. Often this can take the place of a guardianship of the person. The document goes into effect once it is signed and can be terminated at any time by either of the parties.

Durable Power of Attorney for Property

This is a legal document in which a competent adult designates someone (referred to as the agent) to manage his or her financial affairs. There are benefits and drawbacks to this option, but it may be appropriate in certain circumstances. Benefits are that the individual with mental retardation remains competent in the eyes of the law and the court does not have to get involved by appointing a guardian of the estate or property which can be intrusive and costly. However, since the individual remains competent, he or she may enter contracts that may not be in his or her best interests. A "durable" power of attorney stays valid even if the individual becomes incapacitated.

To create a legally valid power of attorney, you need to complete a power of attorney form. Your attorney can prepare it, or you may obtain one from a bank or other source. After you fill out the form, your son or daughter must sign it in front of a notary public. Again, it may

be helpful to have supporting documentation that the individual with mental retardation is competent to designate an agent.

Durable Power of Attorney for Advocacy

In some states a power of attorney for legal advocacy can be created. It is a legal document signed by a competent adult who designates an agent to assist in making or voicing decisions. A form can be drafted that specifies what areas of assistance the individual may need. It can serve as a form of protection, allowing the agent to ensure that the individual understands and is capable of making decisions and providing consent. Like other power of attorneys, the individual remains competent but in need of assistance in making decisions. Parents may consider this option when their son or daughter reaches the age of majority and needs assistance in making decisions about his or her Individualized Education Program.

The Steps in Legal Guardianship

Each state has its own legal procedures or processes in determining the need for guardianship. The following steps are typical:

1. Someone – usually parents or other concerned people – file a petition with the court that has jurisdiction over the person whose competency is in question.
2. The petition is then delivered to that person.
3. The person petitioned for guardianship appears before a judge for a competency hearing. Most states require that the proposed ward physically appear at the hearing. If the person's medical condition prohibits a personal appearance in court, some judges will require a physician's letter, explaining why this person cannot appear in court.
4. The judge bases the decision to appoint a guardian on appropriate evidence. The amount and nature of this evidence may vary with each state. Some states may be willing to establish guardianship based on the family's testimony. Others may require evidence from someone who is outside the family. This can include physicians, psychologists, social workers or other appropriate professionals. In some states, the judge will appoint a representative or attorney to defend the legal rights of the prospective ward.
5. After hearing all the evidence, the judge will rule on whether the person is incapacitated and needs guardianship, and if so, establishes some form of guardianship.

Selection of a Prospective Guardian

It is usually advisable to name a successor (or sometimes called testamentary) guardian in your will. A successor guardian is just that, someone whom you wish to be guardian of your ward after you die or can no longer fulfill the role of guardian.

The person named as testamentary or successor guardian should be carefully selected and should agree to this responsibility. You may want to name your spouse initially. Subsequently, you will want to consider someone who is likely to outlive the ward because the guardianship may continue indefinitely. However, a court will have to ultimately authorize this person before he or she can legally take this role.

Because the designated guardian will have direct responsibility for making decisions about the ward's personal lifestyle, living arrangements, health care and other matters, he or she should not only be personally acquainted with the ward, but also should be a person who knows where to look for advice in selecting services. At the same time, the guardian should view himself or herself as an advocate for the ward and should be able to respect and interpret the ward's own preferences and wishes; these preferences should be balanced with what others might see as the ward's best interests.

You should consider making provisions to cover out-of-pocket expenses incurred by the guardian for travel, for professional consultation and for other activities. These can be covered from the ward's funds, from a trust or in some other way. A guardian's personal concern for a ward can't be bought; assistance with legal technicalities can be, and a guardian should have access to the advice of an attorney and the means to pay for that advice if necessary.

There are certain qualities and characteristics you should seek for the person who will be guardian. While this is not an exhaustive list, the person should:

- Live relatively close to the ward.
- Have enough time to assist this person and carry out the legal responsibilities.
- Be willing to learn about new programs for people with mental retardation and related developmental disabilities.
- Be willing to adapt to changing circumstances.
- Have good property management skills if he or she is guardian of the estate.

While it may be useful for you to prepare a "letter of intent" describing the personality and preferences of your child (see page 29), you should realize that both your child and the circumstances will change. You should place confidence and trust in the guardian to adjust to changing circumstances and not attempt to predetermine what decisions should be made. You should not, for example, try to make a life contract with a residential provider or lock in a specific living arrangement. It is your son or daughter's life, even if he or she will need ongoing guidance or supervision.

A situation may arise where a guardian is unavailable to perform guardianship duties. Some states now allow the guardian to assign the guardianship power to another person for a short period under a power of attorney. This provision of the law is only for genuine, temporary situations such as short-term illness or distant travel by the guardian. If the appointed guardian cannot perform the legal duties, then this person should resign and ask the court to appoint a successor guardian.

Standards for a Good Guardian

As a parent who becomes the guardian of a son or daughter with mental retardation, you are not likely to dramatically change how you interact with or relate to your new "ward." Even though you may have new responsibilities as a guardian, such as record-keeping and periodically reporting to the courts, your daily role with your adult child will likely continue as it did before the guardianship. However, the relationship between a guardian and a ward, the responsibilities

of being a guardian and the decision-making legally given to a guardian does merit further discussion and is an area that any guardian, including parent guardians, should consider.

In the early 1990s, the National Guardianship Association (NGA), a newly formed group of professional guardians, advocates and others adopted a code of ethics and standards of practices to help guide professionals and parents on issues that guardians face, and how to respond to these issues in the day-to-day role of guardian. These standards have been continually reviewed and updated, and today comprise 24 different standards covering areas such as informed consent, confidentiality, conflict of interest, self-determination, and other areas. While many of these standards may be more germane to professional guardians, you or other family members may want to review these standards, which may help provide guidance in undertaking the role of guardian.

You can read or download a copy of the NGA's Standards of Practice from their web site at: <http://www.guardianship.org/pdf/sofp.pdf>.

Public and Corporate Guardianship

There will not always be a parent, other family member or friend to act as guardian of a person with mental retardation. If family members or friends are available, they also may be unwilling, unavailable or not qualified to take this role. For these and other reasons, most states have appointed public guardians or have laws which allow corporate guardianship programs.

Public Guardianship

Some local and state government agencies provide guardianship to people with no family available or willing to become guardian. This is referred to as public guardianship. Nonprofit organizations under contract with the state or local government may also provide public guardianship services.

Public guardians often have large caseloads and time-consuming amounts of paperwork. Some public guardians may also have other duties, so must divide their time between responsibilities. These responsibilities can limit the time and resources public guardians have available to assist their wards. Thus, this type of guardianship is often considered as a last resort, especially for those who have financial resources, or can secure an individual guardian – or get the services they need elsewhere.

State resources generally finance public guardianship. Although states usually have safeguards which free public guardians to advocate for their wards, a conflict of interest could arise if a public guardian should have to oppose another state-funded agency. If public guardianship is being considered for a person with mental retardation, care should be taken to be sure these guardians have the time, resources and latitude to fulfill their responsibilities.

Corporate Guardianship

Many states allow incorporated agencies to provide guardianship and related services to people with mental retardation. In these agencies, the corporation is the guardian and assigns a professional staff person or volunteer to carry out the guardianship responsibilities. These

organizations often provide legal guardianship, individual service coordination, periodic support and even temporary guardianship. Parents can contract with such an agency to start specific services either after they die or when they can no longer help their child. Some state agencies also contract with these organizations for guardianship services. The organization's revenues may come from advanced funding from parents, bequests from the parents' estates, life insurance, United Way funding and contributions or subsidies from other organizations such as chapters of The Arc.

Before contracting with a corporate guardianship agency, you should investigate the organization to be sure it is well managed, has stable funding and provides quality services. There must be adequate proof the program will remain solvent and continue to supply good services throughout the lives of its wards.

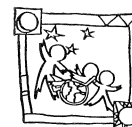
Guardianship Resources

Berkobien, R. (1997). *Future Planning: Guardianship and People with Mental Retardation*. The Arc of the United States. Available on-line: <http://www.thearc.org/faqs/guard.html>

National Guardianship Association, 1604 Country Club Rd., Tucson, AZ 85716 (520-881-6561) <http://www.guardianship.org/> The mission of NGA is to establish and promote a nationally recognized standard of excellence in guardianship.

The National Academy of Elder Law Attorneys, 1604 Country Club Rd., Tucson, AZ 85716 (520-881-4005) <http://www.naela.org/> The National Academy of Elder Law Attorneys, Inc. is a non-profit association which assists lawyers, bar organizations and others who work with older clients and their families. Established in 1987, the Academy provides a resource of information, education, networking and assistance to those who must deal with the many specialized issues involved with legal services to the elderly and disabled.

FOR MORE INFO:



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